

Palliative care

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Definition

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount to provide the best quality of life for patients and their families. Careful assessment of symptoms and needs of the patient should be undertaken by a multidisciplinary team.¹

The World Health Organization defines palliative care as:²

'an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- *provides relief from pain and other distressing symptoms*
- *affirms life and regards dying as a normal process*
- *intends neither to hasten or postpone death*
- *integrates the psychological and spiritual aspects of patient care*
- *offers a support system to help patients live as actively as possible until death*
- *offers a support system to help the family/carers cope during the patient's illness and in their own bereavement*
- *uses a team approach to address the needs of patients and their families/carers, including bereavement counselling, if indicated*
- *will enhance quality of life, and may also positively influence the course of illness, and*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.'*

Rationale

Palliative care requires a multidisciplinary approach with the general practitioner playing a central and increasing role, especially in the management of domiciliary care. For example, in 2002, of the approximate 134 000 deaths that occurred in Australia, about 64 000 (almost 50%) would have been cared for by a general practitioner several times during their last 12 months of life.³

Most patients who die from easily predictable deaths from a diagnosed terminal illness want to be cared for at home (>50%), however, only about 14% are able to exercise this option, as most patients now die in hospital.⁴

The community sector is increasingly caring for people at home rather than in hospital, and general practitioners often coordinate sometimes fragmented and competing community services and advocate on behalf of their patients and their families and carers for community based palliative care.^{5,6}

Like other doctors, general practitioners are largely trained to work with curative or life prolonging models of health and many general practitioners have identified that they require further education in the skills that underpin the practice of palliative care such as basic communication skills, symptom control and management skills and skills for dealing with 'death and dying'.⁷

The provision of good general practice and community based palliative care requires general practitioners to organise their practices appropriately, help build and configure best use of community based health networks (eg. specialist hospital based to community based teams) to meet the palliative care needs of their patients and their families and carers for quality, comprehensive health care at the 'end-of-life' in the setting of their choice.⁸

There are government initiatives into palliative care, and general practitioners need to work in conjunction with government health priorities and other organisations toward better palliative care services.⁹

What are the core elements of general practice palliative care?

Core education requirements for general practice palliative care curriculum need to ensure:^{10,11}

- physical aspects of care – close and detailed attention to symptom recognition and management, and knowledge of the pharmacology of any medications used, including dosing in elderly or renally impaired patients
- psychosocial aspects of care – emotional, social and spiritual aspects of end-of-life care, including developing specific communication skills needed to discuss end-of-life issues with patients and their families/carers
- cultural issues – crosscultural issues, appropriate use of independent interpreters
- ethical issues – state based legal requirement with death, wills and end-of-life issues, including managing requests for euthanasia and requests to hasten death with counselling and understanding
- teamwork – how to work in an multidisciplinary team; how to coordinate different models of care for best patient and family/carer outcomes
- practical issues – practice issues around 24 hour care rostering, appropriate use of Medicare Benefits Schedule to sustainably practice equitable palliative care for patients determined on the basis of need
- carer support – respite arrangements, depression screening and support, emotional support and bereavement care, and understand and recognise risk factors that may predict the early onset of psychosocial distress and complicated grief reactions¹² in family members and carers and appropriately refer for further psychosocial support.

- career long learning – includes critical appraisal of the evidence base used for own practice and developing primary palliative care research skills to update own evidence base, as well as developing community education, advocacy and health promotional skills.
- complementary and alternative medicine^{13,14} – includes developing skills to help patients and their families/carers to be able to assess their own use of complementary therapies from an evidence based and/or safe perspective.
- audit, care pathway and outcome measurement – includes developing skills to measure own practice in the area of palliative care, eg. developing an end stage care pathway audit tool¹⁵ and be able to audit clinician use of symptom assessment lists and outcome measures (eg. pain scales).

The five domains of general practice

– palliative care

Communication skills and the patient-doctor relationship

The general practitioner needs to establish and foster effective and empowering relationships with patients and their families as partners in care decisions, as well as with other health care professionals – as advisors. Effective communication promotes quality care and optimises health outcomes, including within multidisciplinary teams and community organisations, and administrative bodies, and enables general practitioners to be strong advocates for their patients.

The general practitioner must:

- demonstrate good communication skills^{16–18} including active listening, breaking bad news, dealing with difficult questions, discussing end-of-life issues, and crosscultural care at the end-of-life¹⁹
- understand the experience and consequences of disease from the perspective of the patient and their family
- help patients live as creatively and meaningfully as possible all the way to the end-of-life
- be sensitive to differing perceptions and expectations of disease and treatment among various family members
- be aware of spiritual, religious and cultural issues, and
- understand the normal process of grief, help prepare carers for bereavement and offer support during this process.

Applied professional knowledge and skills

The general practitioner needs to be competent in the physical aspects of palliative care including:

- underlying disease process:
 - appreciate and understand the broad range of terminal illnesses (eg. malignancy), neurological degenerative disease (eg. motor neurone disease), organ failure (eg. chronic obstructive pulmonary disease, congestive cardiac failure), and HIV/AIDS
 - understand potential treatments available, both disease specific and for symptom control, including palliative surgery, radiotherapy and chemotherapy
 - anticipate, diagnose and manage potential problems, either disease related or iatrogenic
 - understand indicators of disease progression
- pharmacology:
 - demonstrate a good understanding of drugs commonly used in palliative care (indications, doses, side effects, routes of administration)
 - be familiar with the use of a syringe driver
 - understand implications of renal and hepatic impairment
 - be familiar with dose equivalence of opioids and able to recognise signs of opioid toxicity
 - be aware of possible interactions of prescribed drugs with any complementary and alternative medicines their patients may be taking or be able to refer to available databases to advise their patients on available evidence of efficacy, safety and adverse interactions^{13,14}
- symptom identification and therapeutic responses (including counselling and psychosocial support)
- be able to demonstrate skills in diagnosing, identifying the cause and appropriately managing common symptoms of many end-of-life conditions:
 - pain (nociceptive, visceral, neuropathic and complex)
 - nausea and vomiting
 - constipation
 - anorexia

- hiccups
- fatigue, weakness and lethargy
- mouth care
- delirium and confusion
- dyspnoea
- depression and anxiety
- existential distress
- pressure area care
- managing malignant effusions
- managing peripheral lymphoedema
- terminal phase events, eg. agitation, distress, ‘noisy breathing’, restlessness, haemorrhage and seizure
- be competent in recognising and appropriately managing and/or referring on patients with potential emergencies at the end-of-life such as:
 - opioid toxicity (especially in renal failure)
 - neutropaenic sepsis
 - hypercalcaemia
 - bowel obstruction
 - seizure
 - spinal cord compression
 - haemorrhage.

Population health and the context of general practice

The general practitioner needs to:

- be aware of the services available within the community and the means of accessing these services
- coordinate these services in the care of the patient and also consider health beyond that of the individual patient. This involves an advocacy role regarding community needs, including promoting the needs of disadvantaged groups. Part of this may involve developing crosscultural partnerships
- be aware of the needs for bereavement support, and appropriate referral or management of complicated grief reactions
- help allocate finite health care resources prudently to best serve the health needs of the population on the basis of need and equity of access to care and support.

Professional and ethical role

The general practitioner needs to display a professional attitude and be able to analyse and understand the ethical dimensions of clinical scenarios. This will involve the ability to:

- agree on treatment modalities, and priorities and goals of treatment
- respect patient wishes to decline treatment
- understand issues surrounding euthanasia, ‘relief of suffering’ at the end-of-life,^{20,21} and patient and community perspectives on a ‘good death’²²
- understand issues surrounding advance health directives and end-of-life planning, including the need to complete ‘unfinished business’
- be prepared to advocate strongly for patient needs
- reflect on own personal beliefs and the impact of these on interactions with patients and their care
- have an ongoing commitment to professional development that promotes the best available evidence based practice. This knowledge is used to provide patients with the best management. It is influenced by an awareness of spiritual, religious and cultural issues specific to each patient, which affects not only perception of illness and death, but treatment decisions made in partnership with the patient and their family/carers
- be able to recognise any personal emotional stress and seek assistance appropriately.

Organisational and legal dimensions

The general practitioner needs to:

- demonstrate an understanding of the complexities, and commitment to, working as part of a multidisciplinary team
- be able to work with several models of health care and service delivery, and be able to coordinate and integrate these services collaboratively and seamlessly for the best care of the patient²³
- be aware of local medical, nursing, allied health, community and respite services
- be able to locally access appliances as aids to daily living for patients
- be familiar with state legal requirements for:
 - carer's allowances
 - advance health directives
 - enduring power of attorney/enduring power of guardianship
 - will preparation
- be familiar with identification and certification of death, and surrounding legal issues
- structure practice to accommodate home visits for palliative patients, when appropriate
- be aware of nontime based Medicare Benefits Schedule (MBS) items that reward team care and planning.

Learning objectives across the GP professional life

Medical student

Communication skills and the patient-doctor relationship

- Describe specific communication skills to be able to best care for patients and their families/carers at the end-of-life, and the families/carer's progress beyond the patient's death during their bereavement phase.

Applied professional knowledge and skill

- Describe the pathology, including both malignant and nonmalignant terminal and chronic illness and some understanding of prognosis and quality of life issues.
- Describe the anatomical and physical aspects of incurable, life limiting disease processes.
- Outline how a significant proportion of patients with incurable diseases require the doctor to exhibit skills for 'caring' rather than 'curing' and how to help patients and their families/carers to prioritise care on the basis of quality of life.

Population health and the context of general practice

- Describe the role of GPs in the palliative care setting and GPs operating within a multidisciplinary framework to provide palliative care to patients from a holistic, physical, psychosocial and spiritual perspective.

Professional and ethical role

- Be able to seek help and care for own physical, emotional, social and spiritual needs in this emotionally charged area of work.

Organisational and legal dimensions

- Outline team care and care planning arrangements that are possible for both funding and organising care in a general practice palliative care setting.

Learning objectives across the GP professional life

Prevocational doctor

Assumed level of knowledge – medical student

Communication skills and the patient-doctor relationship

- Demonstrate skills in taking a thorough history (physical, emotional, psychosocial and spiritual) in a patient with a life limiting illness.
- Demonstrate skills in competently communicating 'bad news' and discussing prognosis, and empathically being able to redefine realistic goals for 'hope' and 'care' at the end-of-life.

Applied professional knowledge and skill

- Demonstrate skills in being able to elicit reporting of common symptoms seen in palliative care, be able to use symptom checklists and screening tools when needed, and organise a prioritised management check list in line with the patient's and/or their family's expressed wishes.
- Demonstrate skills in being able to organise appropriate investigations in a palliative patient, taking into consideration the context of the patient's illness.
- Demonstrate skills in being able to perform a thorough examination in a patient with a life limiting illness.
- Be aware of drugs commonly used in palliative care and their indications, doses and routes of administration.

Population health and the context of general practice

- Describe how to assess and describe each patient's links to family and friends.
- Demonstrate an ability to advocate for equity of access to multidisciplinary palliative care services particularly members of disadvantaged groups and their families/carers.

Professional and ethical role

- Demonstrate skills in being able to devise comprehensive management plans in partnership with patients and their families/carers to enhance quality of life at the end-of-life.
- Ensure self care measures are in place for the treating GP and other care team members.

Organisational and legal dimensions

- Demonstrate familiarity with completing death certificates, advanced health directives, enduring guardianship requirements, carer's allowance applications and other legislative and administrative requirements relevant to palliative care and end-of-life issues.

Learning objectives across the GP professional life

Vocational registrar

Assumed level of knowledge – prevocational doctor

Communication skills and the patient-doctor relationship

- Demonstrate awareness in defining the realistic context of illness at the end-of-life for the patient and their family.
- Demonstrate specific communication skills in dealing with end-of-life issues such as giving bad news, counselling regarding realistic expectations and hope, nutrition and hydration, exploring and managing requests for euthanasia.

Applied professional knowledge and skills

- Demonstrate skills in managing bereavement issues for families/carers and coordinating services to meet these needs when ongoing care and support is required.
- Demonstrate management skills in dealing with the psychological, social, cultural and spiritual aspects of the patient's illness, and the impact of these on patient care.

Population health and the context of general practice

- Demonstrate establishment of relationships and networks with other community services that are necessary to provide quality palliative care (nursing, allied health and domiciliary services) equitably across the local population as needed.

Professional and ethical role

- Demonstrate skills in dealing with ethical issues in patient care at the end-of-life.

Organisational and legal dimensions

- Demonstrate the ability to lobby local health service providers to provide essential health services for palliative care patients as needed in the patient's or carer's preferred place of care.
- Demonstrate the ability to advocate on behalf of patients in relation to meeting their palliative care needs.²⁴
- Demonstrate awareness of the palliative care services available in the patient's community, and be able to access these services to optimise patient care.
- Demonstrate familiarity with completing death certificates, advanced health directives, enduring guardianship requirements, carer's allowance applications and other legislative and administrative requirements relevant to palliative care and end-of-life issues in the general practice setting.

Learning objectives across the GP professional life

Continuing professional development

Assumed level of knowledge – vocational registrar

Communication skills and the patient-doctor relationship

- Demonstrate commitment to upskilling regularly in communication skills acquisition associated with managing challenging end-of-life issues for patients and their families/carers.

Applied professional knowledge and skills

- Demonstrate evidence of updating own knowledge and skill base in the light of new and emerging evidence in palliative care.

Population health and the context of general practice

- Describe the demographics of terminal illness especially in relation to nonmalignant conditions.
- Demonstrate commitment to forging and maintaining relationships with other community palliative care service providers to provide equity of access on the basis of need.
- Describe and implement, where appropriate, policies and standards for palliative care, eg. *Standards quality palliative care for all Australians.*²⁵

Professional and ethical role

- Demonstrate planning on how to undertake ongoing professional development in relation to identified palliative care knowledge gaps.

Organisational and legal dimensions

- Demonstrate the ability to identify gaps in own knowledge, skills, and attitudes in relation to evidence based palliative care.
- Outline practice financial aspects and time management issues related to effective palliative care general practice service provision.
- Undertake regular audits of management practices in dealing with palliative care patients and their families/carers.

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